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ABSTRACT

The report of the World Health Organization working group which met in February, 1979, to consider issues in detection of handicap in children contains sections on major problems, early detection programs, approaches, administrative issues, personnel, research, conclusions, and recommendations. Major problems include the definition of handicap and "at risk," second handicaps secondary to other handicaps, and need for services. Early detection programs are discussed in terms of an international survey of existing programs in nine countries, general requirements of screening programs, timing, goals, hazards, and frequency of detection programs for those already identified as handicapped. Primary prevention, genetic counseling, prenatal diagnosis, termination of pregnancy, and the neonatal period are considered in the chapter on approaches to early detection. Administrative issues discussed include program evaluation, psychological considerations, economic considerations, epidemiological considerations, and handicap registers. Health care teams, multidisciplinary teams, parental involvement, and training are personnel topics examined. Types of needed research include small scale research projects, quantitative models, and cross national studies. Among conclusions is the need for surveillance systems though the organization and methods adopted may differ. Seventeen recommendations include: the assessment of all pregnant women for the risk of handicap to the child, examination of every newborn by specially trained staff, detection programs to be limited to those conditions which are identifiable and for which appropriate management is available, and cross national studies in the field of handicap. (DB)

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Early Detection of Handicap in Children

Report on a WHO Working Group

Faro (Portugal)
15-18 May 1979

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WHO WORKING GROUP ON THE EARLY DETECTION OF HANDICAP IN CHILDREN

Faro, 15-18 May 1979

1. INTRODUCTION

1.1 Opening session

A Working Group on the Early Detection of Handicap in Children was convened in Faro, Portugal, from 15 to 18 May 1979 by the WHO Regional Office for Europe. The meeting was attended by 10 temporary advisers from Czechoslovakia, Denmark, Greece, the Netherlands, Poland, Portugal, Sweden, and the United Kingdom and by one staff member from the WHO Regional Office for Europe. Dr Laura Ayres was elected Chairman and Dr C. Sundelin Vice-Chairman; Dr J.D. Williamson acted as Rapporteur.

The meeting was opened by Dr M. Wagner, WHO Regional Officer for Maternal and Child Health, on behalf of Dr Leo A. Kaprio, WHO Regional Director for Europe. The participants were welcomed to Portugal by the Civil Governor of the Algarve, Dr J. Carrapato. The Public Health Officer of Algarve, Dr C. Guimaraes, stressed the importance of maternal and child health to Portugal and outlined the responsibilities of the Minister of Social Affairs in this connexion. He expressed the hope that the Working Group would reach conlusions that would permit the standards of child health to be raised to an even higher level in the European Region.

Dr Wagner reviewed the historical background to the present meeting. Industrialization had led to a reduction in mortality and in birth rates, with the result that health services were now able to concentrate on the quality of life of populations. It was clear to WHO that the quality of newborn children was one of the major features determining the quality of ultimate life, so that the appropriate management of reproduction or childbirth, together with the early detection of disease through mass screening campaigns, had initially been seen as a major concern for the Region. However, the early promises of such an approach had not been fulfilled and the time was ripe for a fresh look at screening programmes that attempted to identify problems at an early stage. The more recent interest in multidisciplinary care was also a feature to be taken into account. He concluded by showing how the task of the Working Group related to the general activities of the Regional Office's Maternal and Child Health unit.

1.2 Scope and purpose

The purpose of the Working Group was to recommend methods for the comprehensive management of programmes in the field of maternal and child health, taking into account health and socioeconomic factors and the consequences of early detection. The Working Group limited itself to discussions on the early detection of handicap in the prenatal period, the neonatal periods (0-1 month), infancy (1-12 months), and in preschool children (1-6 years). Detection of handicap in children above the age of 6 years was excluded from the discussions.

Despite the fact that the title of the report implicitly excluded primary prevention of handicap and the management of handicap, it became clear to the participants that certain aspects of these issues were very strongly related to the subject under discussion. As a consequence, the Group also considered these aspects.

This report begins with a review of the major problems related to the topics under discussion; this is followed by a consideration of detection programmes, focusing particularly upon the perceived relevance and the hazards of such programmes from the point of view of the participating parents. Then some of the features of early detection programmes are briefly outlined before planning requirements for a coherent policy are examined. The imperatives of teamwork and parental participation within an integrated child health care service are discussed, and finally a survey of research needs is presented. From all this, a number of principles emerge, and these are presented together with the conclusions and recommendations of the Working Group.

2. MAJOR PROBLEMS

2.1 Definition of handicap

It is difficult to make recommendations on either the detection or the management of handicap because the term has so many meanings. An early attempt, in the United Kingdom, to overcome this difficulty defines (a) "handicap" as "a disability adversely affecting normal growth, development and adjustment to life over a substantial period of time, if not permanently"; (b) "disability" as "a defect which results in some malfunction but which does not necessarily affect the individual's normal life"; (c) "defect" as "some infection, impairment or disorder of the body, intellect or personality". However, this separation was not found to be very useful because of its heavy reliance on subjective considerations.

Any individual can be considered normal when he is able to participate in a wide range of human activity on equal terms with his peers without requiring special consideration or help from others. Pursuing this idea, it can be said that a handicap is some sort of long-term disadvantage which interferes with the individual's degree of participation in everyday living. Such disadvantages can be intrinsic or extrinsic to the person. An intrinsic handicap is a disadvantage arising from the individual's own characteristics, from which he cannot be separated. An extrinsic handicap is a disadvantage arising from the individual's environment or circumstances (e.g., poverty, maternal deprivation, racial discrimination, residence in a depressed or disaster area). The Eastern proverb, "I wept because I had no shoes until I met a man who had no feet", illustrates the difference between these handicaps and Fig. 1 shows one proposed classification of the major intrinsic handicaps (*1*).

An individual can have one or more extrinsic, and one or more intrinsic handicaps, or he can have any combination of these. One handicap, whether extrinsic or intrinsic, can give rise to further handicaps from either group, and the terms "primary" and "secondary" can be used to denote the relationship between them (e.g., maternal deprivation, which is an extrinsic handicap, can cause a secondary emotional handicap which is intrinsic, while an intrinsic handicap, such as blindness, can cause the extrinsic handicap of poverty). But here we are only interested in primary handicap; secondary handicap will be considered later (section 2.3).

The skills related to human activities are diverse and very few people master all of them. As a consequence, there is an implicit variation in the basic concept of normal functioning which must be taken into account in determining the existence of handicap. Yet, from even this brief review of the subject, it is clear that any defect which interferes with the execution of any skill required in human activity can be said to result in a disability. Such definition depends on the readiness of society to label the individual as disabled. Even then, such a disability only becomes a handicap if the individual concerned is unable to develop compensatory strategies. Whether or not this is possible will depend on:

(*a*) the existence and acceptability of alternative behaviours;

(*b*) the disabled person's own skills which are necessary to allow him to adopt alternative behaviours;

(*c*) the sufferer's own psychological flexibility; and

(*d*) the flexibility and compassion of the community in which the sufferer lives.

Thus, the incidence of handicap is strongly related to the social structure of society, particularly social attitudes and social organization.

Fig. 1 Classification of intrinsic handicaps: key handicaps and components

Key handicaps	Handicap components
1. Locomotor handicap	A. Impaired mobility in environment
	B. Impaired postural mobility (relation of parts of body to one another)
	C. Impaired manual dexterity
	D. Reduced exercise tolerance
2. Visual handicap	A. Total loss of sight
	B. Impaired (uncorrectable) visual acuity
	C. Impaired visual field
	D. Perceptual defect
3. Communication handicap	A. Impaired hearing
	B. Impaired talking
	C. Impaired reading
	D. Impaired writing
4. Visceral handicap	A. Disorders of ingestion
	B. Disorders of excretion
	C. Artificial openings
	D. Dependence on life-saving machines
5. Intellectual handicap	A. Mental retardation (congenital)
	B. Mental retardation (acquired)
	C. Loss of learned skills
	D. Impaired learning ability
	E. Impaired memory
	F. Impaired orientation in space or time
	G. Impaired conciousness
6. Emotional handicap	A. Psychoses
	B. Neuroses
	C. Behaviour disorders
	D. Drug disorders (including alcoholism)
	E. Antisocial disorders
	F. Emotional immaturity
7. Invisible handicap	A. Metabolic disorders requiring permanent therapy (e.g., diabetes, cystic fibrosis)
	B. Epilepsy, and other unpredictable losses of consciousness
	C. Special susceptibility to trauma (e.g., haemorrhagic disorders, bone fragility, susceptibility to pressure sores)
	D. Intermittent prostrating disorders (e.g., migraine, asthma, vertigo)
	E. Causalgia and other severe pain disorders
8. Aversive handicap	A. Unsightly distortion or defect of part of body
	B. Unsightly skin disorders and scars
	C. Abnormal movements of body (athetosis, tics, grimacing, etc.)
	D. Abnormalities causing socially unacceptable smell, sight or sound
9. Senescence handicap	A. Reduced plasticity of senescence
	B. Slowing of physical or mental function of senescence
	C. Reduced recuperative powers of senescence

Source: **Agerholm, M.** Handicaps and the handicapped. *Journal of the Royal Society of Health*, 1: 3 (1975).

The process of socialization within a given culture (*2*) is also important here. The main function of this process, which includes child-rearing and schooling, is the proper integration of the child into his society. It is essentially a community-centred process. On the other hand, a child-centred approach, in which each child is helped to realize his own potential, is difficult to achieve, given (a) the differing directions of development and rates of achievement in different children, (b) the wide variety of skills and attitudes required of teachers in such a highly personalized service, and (c) the difficulties in weighing one child's needs against those of others. Development is not a uniform phenomenon for even the individual child, although children tend to be labelled as normal or abnormal on the basis of only very selective assessments of some of their skills. Moreover, there are those children whose main potential is in fields which are either undervalued or positively opposed by the wider society. Even if those children are very skilled in such fields, their "assessed development" (excluding the aberrant activity) may be so disappointing as to be regarded as evidence of retardation. Any child unable to achieve his potential for one of these reasons is likely to be considered intrinsically handicapped, the extrinsic (i.e., social or environmental) nature of his problem being overlooked or ignored.

Another form of handicap which is essentially social in origin is related to the projection of the standards of achievement on to children. Each society has some sort of graded attainment level, and many have instituted forms of objective evaluation (i.e., examinations) to test children's achievements. Such programmes have inevitably an objective view of intellectual developments; as a consequence, the variable rate of intellectual development is responsible for many "late developers" being classified as abnormal (*3*). Indeed, the child's knowledge of his delayed development and his own fears of failure might stimulate him to assume the identity of a handicapped person quite inappropriately, with disastrous effects on his future performance.

The most pernicious form of projection is that which confuses intellectual development and social integration. This is seen particularly in the concept of readiness for school. Most societies believe that all children of a certain age are ready for schooling, but in every society there is a proportion of chidren who do badly in their early education when compared with their peers. This phenomenon is a function both of the child's intellectual development and of his ability to accommodate to the requirements of the social institution (i.e., the school). When the school entry age was lowered in Greece, the proportion of such poorly-performing children increased.[a] This, of course, resulted in widespread concern over the educational system and the general health of children. However, as yet there is no evidence that poor performance in the first year of school life is an accurate indicator of ultimate

[a] **Maratos, O. Personal communication**

achievement. The problem of integration is much more significant for physically handicapped children whose intellect is unimpaired. There is frequent ambivalence in the reaction of teachers and lay people alike to such children. Sometimes the label of handicap is widened beyond the limits of the objective evidence and the children are expected to fail in every field, so that they are offered neither stimulus nor support for their endeavours. Perhaps worse, the true level of their handicap is sometimes unrecognized so that they are expected to perform far in excess of their own potential. All such inappropriate expectations damage the child's chances of living normally or compensating for his handicap. It is not impossible that they may play a significant part in the generation of secondary handicap (see section 2.3).

If the discussion is limited to children with physical handicap, then these problems can be remedied fairly easily, but when the concept of handicap is widened to include psychosocial defects such as mental handicap, behavioural problems and minimal brain damage, it becomes difficult to quantify the handicap caused and even more difficult to identify an appropriate societal reaction. Indeed, it may not even be possible to identify such defects objectively in any sense at all.

When such basic concepts as defects, disabilities and handicaps are incapable of simple definition, the whole value of establishing programmes to detect them in the wider community must be brought into question. It is obvious that many handicaps are multifactorial and self-perpetuated and any detection programme must take this into account. It will not always be easy to identify the role of various possible etiological factors in the generation of handicap, and cross-national studies incorporating psychological and sociological considerations might be helpful in untangling them. Before these can be undertaken there is a real need to produce operational definitions of the basic concepts.

2.2 "At risk"

Since the final state, i.e., handicap, is almost undefinable in absolute terms, it should not surprise us that the predisposing stage of "at risk" is equally elusive. The risk notion implies that persons with certain identifiable characteristics have a statistically significant higher probability of experiencing a given problem than others without such characteristics. The basic difficulties with this notion are:

(*a*) that most problems are multifactorial in etiology, and

(*b*) that epidemiological data are frequently inadequate to predict risks.

Multiple causation complicates matters, since very few disorders or diseases have been analysed from the point of view of antecedent, accentuating or contaminating variables, etc. (*4*). The weight to be applied to any particular

"cause" or to any specified combination of suspected causes is beyond our current level of medical knowledge. The difficulty in epidemiological assessment is that most health and social services involved in such handicap are pluralistic; not only is it difficult to obtain data, but when they are obtained, they are frequently incompatible and incomplete.[a]

The risk concept is, however, very attractive in terms of detection programmes. It represents an attempt to chart a shortcut to the early recognition of people with potential problems to avoid wasting resources, particularly time, through whole-population surveillance. One such innovative and experimental programme, designed to identify high-risk pregnancies and to relate these, together with subsequently identified high-risk children, in a model culminating in the delineation of a handicapped population at 3 years of age, has been introduced in Czechoslovakia.[a] Despite the fact that the best obstetric and paediatric assessment procedures were adopted in this model, and despite the use of the most recent epidemiological data avilable, the results of the risk ratings were not encouraging. The proportions of persons "at risk" during various stages of the model were: 5% during pregnancy, 8% during labour, 10% in the neonatal period, and 20% having defined abnormalities or potential abnormalities at 3 years of age. However, there was considerable interchange between these groups; the data provided showed a sensitivity of 83% but a specificity of only 50%. The predictive validity of the "at risk" category was only 25% when deaths were excluded, but this is expected to increase with refinement of the assessment methods used.

Risk registers have been used in the United Kingdom for many years, although the failure of the "at risk" concept to predict subsequent handicap has led to their abandonment in their original form. At the outset, the idea of risk registers was to pinpoint people with potential handicaps at an early stage. Their main failure was related to an inability to separate out two distinct populations (*5*), namely:

(*a*) the child "at risk": some children are at increased risk of subsequent handicap because of inherited disorders or adverse environmental influences during foetal life or early infancy;

(*b*) the child with false positive risks: within the risk registers there are a large number of children who, while belonging to groups of the community from which most handicapped children would arise, are not themselves in jeopardy of developing such handicaps.

The combination of these two groups of children on the risk registers led to poor objective perfonnance of the registers themselves and to an unduly large number of children being monitored. On the other hand, such risk

[a] **Stembera, Z.** Personal communication.

registers do confirm the similarity of many handicapped children (although we do not fully understand these similiarities), and they do sensitize the caring professions to the problem of handicap. Now, perhaps more than ever before, there is an urgent need to delineate and quantify the risks associated with defined handicaps.

2.3 Secondary handicap

Secondary handicaps are defined as those handicaps which are generated by pre-existing handicaps or those which are a consequence of the handicap detection process.

Most handicaps can generate subsequent handicap related to the various ways in which society perceives, reacts to, and accommodates its physical environment for handicapped people. Some of the problems of the handicapped person have been cited in section 2.1. Other obvious examples are (a) the lack of sports and recreation facilities for the congenitally limbless child; (b) society's preference for institutionalizing handicapped people in special centres rather than striving to achieve their integration in the community; and (c) the tendency for subsequent health or social problems to be ascribed indiscriminately to the pre-existing handicap.

Public reaction to handicapped people can also have adverse effects. If the handicap is not obvious, then people will have expectations that the individual will react and behave normally. If the handicap prevents this, conflict may be generated, and this sort of experience early in life may stimulate the handicapped person to adopt avoidance behaviours which will limit social interaction and subsequent development. On the other hand, if the handicap is obvious, the sufferer will be exposed to a wide variety of reactions, ranging from guilt that a particular community should produce handicapped people, through annoyance that the handicapped person is an obstruction in everyday living, to overt sympathy and helpfulness. The result may be just as disastrous from the point of view of social integration.

The most appropriate model for rearing a handicapped child is self-realization. In this, the approach to development and achievement is effectively child-centred and attention is paid to the optimal conditions for ensuring the handicapped child's fullest involvement in his social and physical environment. This model implies that the child should be accepted along with his handicap. It further implies that the child and the family have to relinquish many "normal" expectations and must learn to cope with the often inappropriate expectations of the wider society. The basic problem inherent in this model is the distress consequent on accepting a reduced level of personal functioning when it is quite easy to see that society favours normal or well-adapted (i.e., non-handicapped) people. It is this need to reduce their expectations, together with any coincidental guilt feelings, which is the main problem for parents facing the prospect of a handicapped or potentially

handicapped child (6). Difficulties they face will be reflected on to the child, who will learn from a very early age that he is different, a situation not helped by overprotection by the parents, designed to assuage their own feelings of guilt rather than to help the child adjust to his handicap. It is clearly better for the parents to be reconciled to the situation, where possible in advance of the birth of a handicapped child, and prenatal screening has an important role to play here. In this case not only can the family come to terms with the idea of having a handicapped child before it is born, thereby avoiding some of the major problems of rejection or secretion, but they can start negotiating appropriate expectations with their friends and relatives. The early detection of future inevitable handicap in an apparently normal child has similar advantages in avoiding crippling secondary handicaps imposed by the reaction of loved ones.

A major problem faced by the parents of handicapped children is the unexpectedly negative attitude of doctors and nurses to handicap. Frequently, and for the best of motives (i.e., the wish to protect the mother from knowing that she has a handicapped child for as long as possible during a time of acute stress like the immediate postnatal period), they may resort to such bizarre mechanisms as wrapping the baby up tightly to hide the handicap or taking the baby away for "special observation". This, however, does not help the mother or family to come to terms with the handicap and there is some evidence that the greater the delay between diagnosis and informing the parents, the less is the possibility of the parents being reassured by subsequent professional statements.[a]

To a certain extent, it is easier to accept severe abnormality which is obvious to all and which has easily identifiable manifestations than it is to accept minor and unquantifiable problems (e.g., minimal brain damage). In these situations the child is widely perceived as being "normal" with episodes of aberrant behaviour or emotional instability. Laziness, clumsiness, inattentiveness, aggressiveness, sulkiness and poor motivation are all terms which have been applied to children with such physical, emotional or social handicaps. Parents will not automatically be granted those supportive services available to parents of the obviously handicapped child and may suffer considerable strain through social pressures from various social institutions or their friends. The caring professions (including teaching) often deny the existence of a problem which is manifested only at home. This will contribute to the false negative rate of detection programmes, to be discussed later (see section 3.4). The self-realization model will not necessarily be applied to such a child and he will be expected to react in a normal fashion; such behaviour may be completely beyond his abilities. He may well be classified as deviant and punished accordingly.

[a] **Kalverboer, A.F.** Personal communication.

Perhaps the only mechanism parents can invoke to avoid these problems is to medicalize the condition and to present the child to the health service for subsequent diagnosis. This has encouraged professionals to apply labels to such children despite the fact that many of these minimal handicaps are not amenable to diagnosis. The medical profession is most often chosen because the medical model is specifically designed to label a problem (i.e., diagnose ready for treatment), the implication being that once a label is attached the problem is legitimized as a disease. However, medicalization and labelling both raise problems in terms of widening the role of the health professions and in terms of the future social roles of the labelled individuals. It is by no means certain that the original risks of the handicap being ignored are any worse than the risks of being inappropriately labelled as "abnormal", whether this labelling is medical or otherwise.

The other major division of secondary handicaps, those related to the detection process itself, fall into three main categories:

(*a*) those relating to the way in which professional workers respond to the handicap, reinforcing negative attitudes and guilt in the parents which are subsequently projected on to the child (as outlined above);

(*b*) those relating to the delineation of an "at-risk" group;

(*c*) those relating to the hazards of subsequent investigation and treatment (particularly for those children who prove to have been falsely suspected of being potentially handicapped).

"At risk" is a curious state. It is not well established in the sociological or psychological literature and society does not yet have a specific reaction to it. It is by no means clear how people should respond to those "at risk". The "at-risk" role (7) is applicable to that section of the population who are not diagnosed as ill but who are recognized to be exposed to an above-average level of risk as regards the development of specified problems. Individuals "at risk" may know of their special status or, if they are children, their parents may know and this can have a number of consequences. First, there is the issue of cognitive dissonance, which is the inconsistency between what an individual knows or thinks is appropriate behaviour and how he actually behaves. A pregnant woman who is "at risk" from smoking can decide either to abandon the habit or to rationalize it by citing the tendency of doctors to exaggerate hazards. This may lead parents to have an uncooperative attitude to the health services in general.

The second danger, and one which is more applicable to the age group under consideration, is that the parents will consider the child to be not "at risk" but abnormal. In one screening programme to detect potential abnormalities of the heart, a number of children were defined as "at risk" for a period of observation, after which the diagnosis was amended to

"normal". Subsequent interview revealed the fact that, despite the negative physical examination and the physician's reassurance, the parents continued to treat the child as though he had heart disease.[a] The same phenomenon is common in overprotected children who are regarded as "delicate" by their parents. Any detection programme should take into consideration the consequence of unnecessarily defining children as being "at risk".

Detection programmes may not of themselves endanger patients, but the subsequent assessment or treatment of confirmed, or suspect, cases may well do so. This problem is clearly more acute in the case of false positives. It is now believed that in certain screening programmes for breast cancer there has been more malignancy caused by the use of "hard" radiation in the assessment process than has been discovered in the entire programme.[a] It is not clear how common this sort of problem is in the early detection of handicap, but one obvious hazard occurs in the monitoring of the newborn infant in the special care unit away from the mother. It is now well established that the separation of newborns from their mothers immediately after birth has significant effects on infant behaviour, both in the short term (*8*) and in terms of the mother's reaction to her baby during the childhood years (*9*). Although it is not impossible to avoid observation of "at-risk" infants in such special units on all occasions, there is undoubtedly a place for greater involvement of the mother.

In view of all this suggestive evidence, it is strongly recommended that the potential hazards of all aspects of detection programmes be carefully examined so as to abandon those which have nonremediable effects and which have more hazards than beneficial effects, and to vary the procedures of others in order to minimize the effects of the hazards.

2.4 Provision of services

Up until the beginning of this century the health of children was generally undervalued. In part, this was related to the high mortality they suffered as a result of infectious diseases and malnutrition, but it also reflected the general ethic prevailing in Europe at that time, which placed maximum stress on the individual's ability to work. It was only when the long-term consequences of child illness became apparent that child health services began to appear. In the United Kingdom, for example, the stimulus for such development was the high rate of rejection of army recruits on the basis of handicap (*10*)! In the absence of an integrated service for children there developed a wide variety of partial facilities, gaps being filled by the voluntary sector.

During the present century an increasing awareness of the importance of child health from the point of view of subsequent adult morbidity has led to

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[a] Wagner, M.H. Personal communication.

the development of health services for children in many countries. Maximum emphasis was placed on early discovery of handicap or potential handicap. The main difficulty here was that there were few data on which to base the service; what information that existed was not used since evaluation was not rated so highly as it is today. As a result, surveillance programmes were developed based on the emotional need to do something rather than on the effectiveness of the proposed programmes.

The need to create child health services in any given country necessarily implied the adoption of a uniform standard of service. Since there was little objective evidence that would allow planners to identify aims and consequently to identify strategies, approaches taken by different countries have varied tremendously (*11*). However, it was soon recognized that child health was a function of diverse factors which included nutrition, local environment and relative poverty. There being no conceptual model on which to base decisions, the standards of the service in the areas with the greatest need were raised and they became the basic national minimum, the baseline for the subsequent development of the national child health service. As time passed, standards were gradually and uniformly raised.

This type of programme development has had three major implications:

(*a*) existing programmes are justified in terms of traditional values rather than in terms of evaluated outcome and, as additional exercises are added to the programme in an attempt to increase standards of performance, the chance to test the assumptions of the initial programme, or to evaluate the additional elements, has been wasted;

(*b*) disparities in the effectiveness of various national programmes exist because of social and environmental issues whose effects have not been fully considered;

(*c*) the development of "global" national policy has stifled initiative and innovation in the development of services and, even where experimentation has been attempted, has acted as a disincentive of fundamental change for researcher and administrator alike.

This lack of evaluation, not of any one programme but of the wide variety of national programmes, demands comparative cross-national research into outcomes.

There is too little published research to allow the Working Group to assess the value of contemporary handicap detection programmes in the European Region. The evaluations that are available have tended to be local and problem-oriented rather than universally applicable. One such local study, however, was undertaken in Sweden, when additional procedures had been added to the standard detection programme on the basis of the perceived shortcomings of that programme. Participants were monitored in

terms of the subsequent development of handicaps and of their general health. Preliminary data suggest that the impact on health of this additional progamme is negligible.[a] If this result were generalizable, to the extent that it could be shown that the ultimate state of health or the subsequent development of handicap were independent of screening as a whole, then the whole question of the provision of such services would need to be reexamined. In advance of this sort of research-based conclusion, one valid starting-point would be a comparison of various national programmes in terms of their effectiveness and efficiency.

3. EARLY DETECTION PROGRAMMES

3.1 Survey on early detection of handicap

In preparation for the meeting of this Working Group, a consultant visited nine countries in the WHO European Region to survey existing programmes for the early detection of handicap (*11*). The essential features of this study have been included in this report. If, however, more detailed information is desired, a copy of this study may be obtained from the WHO Regional Office for Europe, Copenhagen (document ICP/MCH 012/6 – English only).

3.2 General requirements

The general requirements of screening programmes have been discussed elsewhere (*12*), but some of the main points are so important that they need to be reiterated here. The most important is that the programme should be restricted to detecting clearly identifiable conditions for which appropriate management is available. There is little purpose in detecting even the most obvious defect if its impact on the sufferer is either negligible or uncertain. In these circumstances detection is maximally useful in research, though it may also be useful in those conditions or syndromes where specific defects, when present, have a high predictive value for future prognosis. The identification of syndromes should therefore be a high priority for future clinical research. It is worth recalling that, although approximately 3000 so-called syndromes are described in the contemporary paediatric literature, a primary defect is known in only about 20% of these.

[a] **Sundelin, C.** Personal communication

It is mandatory that it should be possible to improve the duration or quality of life for any person in whom a defect is found through screening. The Working Group considered that there were considerable differences between such programmes designed for children and those for adults. In particular, it was thought that the concept of treatable disease used as the prime objective for adult screening activities should be expanded to include reassurance and support for the family as a whole, even where the detected defect was not treatable in the medical sense. Pregnancy and childbearing are stressful, anxious times. First-time parents harbour doubts about the perfection of their unborn child, its chances of survival in the birth process and its ability to grow and develop to its full potential. Any detection programme designed to allay parental anxiety could be justified in terms of this outcome alone, provided that this was stated to be one of its main objectives and was evaluated as such. The Working Group felt that these additional dimensions of detection programmes should be positively encouraged.

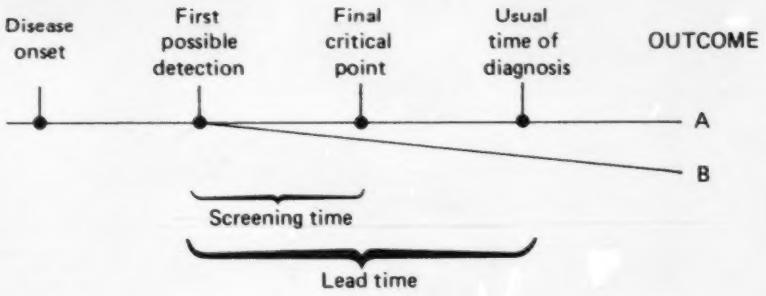
3.3 Timing

There is nothing to be gained in screening for diseases whose onset is quite obvious. Detection programmes should be restricted to those conditions in which there is a considerable time-lag between disease onset and the usual time of diagnosis. In this period there are usually a number of critical points which determine both the severity of the disorder and the success of any treatment in reversing the disease process from that point onwards. There is clearly little value in detecting disease in advance of the usual time of diagnosis unless such detection precedes the last critical point beyond which treatment would be unsuccessful and/or permanent damage would be done. Detection programmes should therefore concentrate on those conditions where the time-lag between the disease's onset and its final critical point is sufficiently long to be suitable for population screening. In particular, the period between the first time at which the disease can be detected and its last critical period (i.e., screening time) should be long enough to permit the delays usually to be expected in any programme at which screening is offered to people of a specific age (see Fig. 2).

3.4 Goals

Fig. 2 shows two possible outcomes for a given disease process: A is the usual outcome of the disease in those situations where no detection programme exists, and B is the outcome to be expected when the disease is detected at the earliest possible moment. The benefits of the programme are therefore B-A. The Working Group recognized that the benefits of the programme must be seen in terms of its outcomes; not only those required of the service by the professionals involved but also those wanted by the

Fig. 2. Model for early detection programmes



parents. It is necessary for the complexities and costs of any detection programme to be viewed against the benefits accruing therefrom, but this equation should include both the purely economic factors of objective cost-effectiveness and the subjective, judgemental outcomes implicit in family support or counselling programmes. The efficiency of any programme should therefore be inferred from its benefits in terms of those goals deemed to be important in relation to the costs incurred by it.

Most detection programmes have long-term goals related to the prevention of disease or handicap later in life. The Working Group felt that, in the particular case of screening programmes for children, consideration should also be given to short-term goals. These would include: (a) health education regarding normal development, handicap and known risk factors; (b) the provision of information about child health and development; and (c) family support encompassing families into which a handicapped child was expected to be or had been, born, families in which one or more persons were identified as "at risk", and "normal" families.

Parents should be encouraged to play a full and active role in their child's development. It follows, therefore, that they should be given the opportunity to participate wherever possible in the detection programmes, especially those which rely on surveillance techniques. Many parents are not ready for such activity and few have had formal training in these subjects. Consequently, health education in primary and secondary education should include information on the normal patterns of development and child-rearing. For the benefit of parents who have not received such education, it would be helpful to establish advice centres within the context of an integrated health service where information and advice, particularly on psychological matters, could be obtained directly and easily. Consideration needs to be given to the role of psychologists in this type of patient-initiated contact.

In most countries of the Region such short-term goals have infiltrated the early detection programmes. In any subsequent evaluation of the service offered, the importance of those goals, the way in which they are pursued, and the impact (i.e., enhancing or otherwise) on the overt objectives of the total programme should be taken into account and codified for the purposes of future monitoring.

3.5 Hazards

The main problems here relate to the specificity and sensitivity of the various elements of the detection process. False positives picked up in a detection process, referred for assessment but subsequently discovered to be normal or unaffected are common problems. The subsequent assessment is costly in terms of both professional time and the money and resources required for full investigation. In many cases the investigations undertaken in the assessment stage are quite hazardous in themselves and there is an ethical problem in offering such tests to all patients identified during the course of a nonspecific detection programme. From the point of view of the families, the anxiety following a referral for full assessment is considerable and should not be tolerated unnecessarily. This anxiety may have secondary effects in that, if projected on to the child, it may impair the child's performance during the assessment (particularly in psychological or educational screening programmes) or it may be dysfunctional to the child's subsequent development. It is possible that the parents may react to the identification of a possible problem in their child in an overprotective way and this reaction may persist after the assessment examination and investigation. The likelihood of this happening is not necessarily diminished by a reassuring result or interview by the assessment team (see section 2.3 above). Methods of allaying parental anxiety are an important part of any detection programme, but to some extent such anxiety can be minimized by avoiding delay between the detection of a possible problem and its elucidation at assessment centres.

The false negative rate of any programme is its most important feature. While most early detection programmes claim to have a negligible false negative rate, the true picture is by no means clear. The identification of a child who remains "at risk" as normal may dissuade parents (or the child) from attending for subsequent surveillance, and this might have a substantial impact on the child's future health when defects go unnoticed. However, the single most serious problem of the false negative result is its effect on the parents. Most contemporary European detection progammes look at their outcomes in terms of their professionally-stated objectives; parental objectives are not often considered. Even with professional reassurance that no abnormality has been found in their child, the parents may well continue to perceive problems in that child's development or behaviour. The Working Group felt very strongly that if a parent perceived or experienced a problem

in their child, then a problem existed *de facto*. Services may well be able to respond to a certain extent by increasing the counselling and reassuring element of their work, but it is likely that widening the scope of the programme to permit families to discuss such problems (as outlined in section 3.3 above) would be more appropriate.

3.6 Periodicity

A major question to be considered in early detection programmes is the frequency of examination. Detection programmes not only have to consider the most appropriate time to screen for pre-existing conditions (whether manifested or not); they must also take into account the possibility of defects developing throughout the preschool period. The options are to achieve a balance in the detection rate of the two groups by selecting some appropriate midpoints for the examination or by devising a programme of multiple examinations whose content will vary according to the degree of probability of the conditions being sought.

3.7 Detection programmes for the handicapped

The handicapped population should not be ignored in the detection programmes. Not only are such people at risk of developing secondary handicaps, but they are at least as likely as the normal population to develop additional handicaps later in life. These handicaps may be linked to the original handicap in some way, or they may be totally independent. The risk of developing such additional handicap is heightened by the fact that most people, professionals and laymen alike, seem to expect the handicapped person to be abnormal in all respects. It is important to stress that the total sum of normal function and behaviour in the average handicapped person is greater than the sum of abnormal function and behaviour (see Fig. 1). It is crucial that all detection programmes applicable to the handicapped person should recognize the true consequences of existing handicaps and the significance of deviations from such "normal" functioning. This brings us to a most important principle: that the handicapped person is a human being in his own right and should be able to expect that society, and the caring institutions established by society, would be able to accept and recognize his limitations, to prevent these increasing by deterioration of his condition or by superadded problems, and to strive to enable him to live a socially useful and maximally normal life. To achieve this, society will have to accept the value of integrating handicapped people into the normal population inasmuch as this is possible. Neither detection nor caring programmes should detract from this general principle.

4. APPROACHES

4.1 The handicapped population

Between 4% and 7% of live-born babies have one or more defects of varying severity which can be detected at birth or during infancy, while 0.5% of all newborns have a chromosomal defect and 0.3%–0.5% have a metabolic disease of genetic origin (*13*). Some 3% of all children are known to suffer from defects of the central nervous system (e.g., epilepsy, cerebral palsy, hydrocephaly, mental retardation and minimal brain damage), but it is estimated that only one-quarter to one-half of these have suffered birth trauma.[a]

4.2 Primary prevention

Detection programmes fall into two categories. The first consists of those designed to discover evidence of nonpreventable disease (e.g., Down's syndrome, phenylketonuria) for which there is appropriate management, using the latter term in its broadest sense to include counselling, abortion, dietary regimens, etc. The second comprises those designed to uncover evidence of disorders which can be prevented. Obviously, the main aim of the health service should be primary prevention, but detection is appropriate when such primary preventive campaigns have a poor outcome because of:

(*a*) multiple influences (e.g., the influence of smoking as one risk factor for low birth weight);

(*b*) poor uptake or low compliance (e.g., vaccination against rubella); or

(*c*) nonavailability of preventive programmes (*vide* the variation in the provision of hypothyroidism detection programmes in the Region).

The Working Group believed that due consideration should be given to the optimum relationship between primary preventive programmes and secondary preventive (i.e., detection) programmes whenever the latter are under discussion.

4.3 Genetic counselling

The Working Group noted the wide variation in the provision of genetic counselling services throughout the Region. It also noted that, while the existing knowledge of genetics is far from complete, it is expanding rapidly.

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[a] Sundelin, C. Personal communication.

To continue this trend and to form the basis of an effective future counselling service, consideration should be given to the use of preventive genetic registers (*14*). Such registers are analogous to "at risk" registers because they identify people who are apparently healthy but who risk transmitting inherited disorders to their children. Until recently such registers have been usually restricted to recording chromosomal disorders, and sex-linked ones at that, but current research into the analysis of HL-A types has shown that we all have potential markers of disease susceptibilities which extend beyond the boundaries of traditional medical genetics. In the near future these markers may be registered at an early age to make possible the prospective detection of many more conditions and the value of a genetic register in defining the main groups "at risk" could then be quite enormous (*15*).

Due consideration should be given to the integration of such expanded genetic registers in future detection programmes. The ethical problems implicit in such a policy should be recognized and the question of data protection must be taken into consideration.

For the time being, the information already available should be put at the disposal of those people "at risk" of transmitting inherited diseases. They should be offered all the investigations currently available and should have access to competent advice about future risks. This is a stressful situation for families, and it is important to include in any genetic counselling team one professional who is viewed by the family as a person of trust. In many countries this will be a paediatrician or a general practitioner, but other possibilities cannot be excluded.

4.4 Prenatal diagnosis

This includes the detection of maternal conditions which may affect the foetus as well as the detection of a damaged foetus. The obstetrician has a major role in reducing the frequency of handicap in the population, though it is only in congenital anomalies, severe physical and severe mental disabilities that data exist to justify an obstetric detection policy. For milder forms of handicap such clear data do not exist, apparently because of the lack of a consistent definition of the handicaps under consideration. Table 1 illustrates the influence of various etiological considerations in perinatal morbidity.

From this table it is clear that abnormalities of pregnancy are a major etiological factor in all principal types of handicap. By far the most important of these abnormalities are prematurity and intrauterine foetal hypoxia.[a] Table 2 demonstrates the relationship of various risk factors with perhaps the most significant group of handicapping disorders, those of the

[a] **Stembera, Z.** Personal communication

Table 1. Influences of known etiological agents on perinatal morbidity

Known etiological agents	Congenital anomaly		Cerebral palsy	Neuro-motor defect	Mental retardation	
	Severe	Mild			Severe	Mild
Genetic	+++	+	0.3	+	1.6	+
Abnormalities of pregnancy	+	+++	2.1	+++	1.2	++
Postnatal abnormality	–	–	0.1	+	0.2	+++
Perinatal morbidity per 1000 live births (approximately)	15	40	2.5	40	3	30

Source: **Stembera, Z.** Personal communication

Table 2. Influence of perinatal risk factors on the development of neurological disorders in the foetus

Risk factor	Significance of the relationship*	
	All disorders	Disorders, excluding prematurity and maternal Diabetes mellitus
Acute hypoxia	++	NS
Chronic hypoxia		
Diabetes mellitus	+++	–
"Small for dates"	+++	+++
Toxaemia of pregnancy	+	+
Prematurity		
Less than 34 weeks	+++	–
34–37 weeks	+	–
Obesity	++	+
Excessive weight gain	+++	+
Breech presentation	+	+

* Levels of significance are +++ $p = 0.005$; ++ $p = 0.001$; + $p = 0.05$

Source: **Stembera, Z.** Personal communication

central nervous system. From this it is evident that chronic intrauterine hypoxia is by far the most significant cause of neurological damage in the absence of prematurity or maternal diabetes. Acute hypoxia treated in good time is only important when associated with prematurity. Good obstetrical practice must therefore concentrate on avoiding prematurity and placental insufficiency.

It should be recognized that, while prematurity is common in all social groups, chronic intrauterine hypoxia is particularly common in the lower socioeconomic ones. The main reason for this is the combination of obesity, cigarette smoking, maternal age, and previous unfavourable obstetrical history (including a higher probability of having suffered spontaneous abortion or perinatal death) in this group. By concentrating on such "at-risk" populations, the obstetric services can improve the efficiency of their detection considerably. All such high-risk patients should be monitored for the development of obstetric complications and their confinement should occur in hospitals with appropriate supportive services. Patients determined to be not "at risk" should be monitored by appropriate means and decisions about the subsequent confinement should depend on the outcome of antenatal surveillance.

The methods useful in monitoring a suspect pregnancy depend on the stage of that pregnancy. In the first trimester there are three basic investigations: amniocentesis, foetoscopy and ultrasonography. All of these can be useful to detect chromosomal deficiencies and congenitial anomalies; analysis of amniotic fluid obtained during amniocentesis can enable the diagnosis of several chromosomal and metabolic diseases to be made in advance of the birth. The advantages of such early detection are that the "at-risk" parents can be informed of the likely outcome of the pregnancy (i.e., if the test is negative, then the probability is that the child will be normal, while if the test is positive the child is likely to be abnormal). If the test suggests an abnormality, then the parents can be appropriately counselled well in advance of the delivery. Arrangements can also be made to prepare for the confinement of the pregnant woman (including induction if this is likely to be necessary) and the early management of the newborn handicapped child. Thus, the major benefits of the first trimester screening are in terms of family counselling and prevention of environmental risk for the foetus, together with the possibility of therapeutic abortion.

However, there are hazards in all of these tests, some of which are not fully quantified as yet. The tests also have false negative and false positive rates, as implied above, and these are not negligible. The danger of damaging a normal foetus, of falsely reassuring the mother of a defective foetus, or of engendering anxiety in the mother of a suspected handicapped but normal child are all hazards which should be considered. Wherever possible they should be discussed with the pregnant woman and her family.

A final problem is that it is by no means certain that current policy regarding first trimester screening is correct. In the United Kingdom, where

the number of congenital anomalies is monitored, a decrease in occurrence of Down's syndrome has not been observed despite the fact that this is one of the main indications for amniocentesis (*11*). In a Danish study the same frequency of chromosome abnormality was found among women with an increased risk and who would normally be offered amniocentesis as among those with no such increased risk who would not normally have been offered the screening (*11*). In the absence of good evidence to support these aspects of the detection programme it is difficult to suggest a global policy for their introduction. Further research is clearly needed.

In the second trimester, obstetric monitoring concentrates on the prevention of prematurity, and in the third on placental function tests to avoid chronic hypoxia. There is a wide and somewhat bewildering variety of methods used in this connexion (see Fig. 3), and this suggests that there is no single test adequate for predicting the "at-risk" pregnancy. Further consideration should be given to the evaluation of second and third trimester detecting processes, both singly and in groups. To this end, simulation models may be of use (*12*).

Fig. 3. Commonly used tests of foetal maturity or placental function

Tests of foetal maturity	Tests of placental function
1. *Clinical*	1. *Hormones*
Naegele's calculation from LMP	Urine: oestrogen, pregnanediol
Uterine palpation	Plasma: oestriol, progesterone
Foetal movements	Serum: human chorionic somatomammotrophin
2. *Amniotic fluid*	2. *Enzyme*
Cytology	Heat-stable serum alkaline phosphatase
Creatinine	Cystine amino-peptides
Urea	
Osmolarity	
Lecithin or lecithin/sphyngomyelin ratio	
3. *Radiology*	3. *Serial cephalometry*
4. *Foetoscopy*	4. *Hypoxic stress test with external cardiotocography*
5. *Ultrasonography*	

Source: **Stembera, Z.** Personal communication

When abnormalities or potential abnormalities are detected there is quite a lot an obstetrician can do. It may be possible to act directly by introducing an artificial energy supply to the foetus. If the cause of the problem is maternal disease, then this can be treated. However, it is more likely that obstetric interventions will be indirect, using such methods as inhibiting contractions in prematurity or by inducing labour (or performing Caesarian section) in chronic hypoxia. Nevertheless, the lack of adequately proven tests, together with the undoubted risks of unnecessary intervention in pregnancy, demand that the pregnant woman and her family should be consulted in advance of the investigation. Wherever possible this consultation should include the transmission of information regarding the justification for the proposed examination, its form and its hazards as well as the therapeutic possibilities existing on its completion.

4.5 Termination of pregnancy

In many countries the artificial termination of pregnancy is still illegal. Nevertheless, where termination is a possibility the pregnant woman who is deemed to be "at risk" should be informed of this in advance of the prenatal detection process, so that she may take it into consideration when deciding whether or not to participate in the detection process.

It should be emphasized that abortion is not the sole justification for prenatal screening. Even if termination of pregnancy is impossible in a particular society, the advantages of early detection from the point of view of environmental control and family support are still immense. This should also be explained to the pregnant woman (*16*).

4.6 The neonatal period

Birth injuries occur in 1%-1.5% of children and the effects of these are made worse by dysmaturity, asphyxia or jaundice. It is clearly mandatory for all such children to be treated quickly and effectively by specially trained staff. If separation from the mother is necessary, steps should be taken to encourage the mother-child bonding. In addition, all children, whether they are the product of "at-risk" or of non-risk pregnancies, should be carefully observed during the first few days of life. Such observation should include a clinical examination performed as early as practicable after birth by a person properly trained in the examination of the newborn. Any abnormality or suspected abnormality detected during such examination should be referred for specialist assessment without delay.

Apart from clinical examination, there are a few inherited metabolic diseases where early detection by biochemical or haematological means is possible. Phenylketonuria, galactosaemia, hypothyroidism and thalassaemia are some of the more obvious diseases which can be detected with relative

ease and economy. However, as with prenatal screening, the full effects of such a detection process on the child and its family should be taken into account and discussed with the family before it is invoked.

4.7 Health and developmental surveillance

There is a wide variety in the organization of such surveillance systems within the Region (*11*), and their effectiveness has not been evaluated. Some children are known to reach school age having problems with sense organs or with psychosocial handicaps which have not been detected during earlier examinations (*17, 11*), but whether this is a failure of the system or evidence of the continuing incidence of new handicaps is not clear.

Experience shows that if children are not examined in the first 2 or 3 years of life, more than one-half of them will later have developmental problems (*18*). On the other hand, many of the abnormalities detected at the age of 4 years are already known to the professional personnel involved in the care of the child (see Table 3). The majority of newly detected abnormalities relate to speech, vision or hearing defects and emotional problems, many of which cannot be properly assessed before the child is 4 years of age and some of which may not have existed earlier. If we exclude all those conditions known to, or suspected by, the parents, then it seems that fewer than 10% of abnormalities found at this age are in the category of newly diagnosed defects[a]. In any case, the rate of severe abnormality is low, at best less than 1 in 4, and most of these abnormalities would be relatively insignificant.

Table 3. Health problems per 100 children at 4 years of age

	Previously known	Newly detected	Total prevalence
All health problems	9.9	14.7	24.6
Slight	4.9	9.3	14.2
Moderate	4.0	5.1	9.1
Severe	1.0	0.2	1.2
Selected problems			
Vision	2.5	4.3	6.7
Hearing	0.3	1.3	1.6
Speech	0.3	1.5	1.8
Neurological	0.6	0.1	0.7
Physical (other)	5.4	4.5	9.9

Source: **Sundelin, C.** Personal communication

[a] **Williamson, J.D.** Personal communication

All this suggests the importance of using an approach to health surveillance very different from that of normal clinical practice. It is not appropriate to act as though scrutiny is the sole purpose of such detection programmes. This will result in boredom in the scrutineer, and in a high rate of false positives in a feeble attempt to justify the scrutiny. Health surveillance can be performed by a single professionally qualified person or by a number of paramedical technicians with specific duties. It is by no means clear which is the better course. The question of who should detect physical abnormalities, hearing deficiencies, visual impairment and difficulties with speech or language requires further elucidation.

On the other hand, most handicaps benefit from early diagnosis. It should be possible to detect all cases of strabismus before the age of 6 months. Most visual defects (including amblyopia) can be detected before 4 years. With modern assessment methods it is possible for hearing function to be examined in the second half of the first year, though pure tone audiometry needs to be performed later in the preschool years. In all these conditions, early treatment has considerable advantages in terms of the final results of available treatment and the subsequent intellectual and social development of the child.

Developmental surveillance is more complicated since it deals with a normal process remote from the main interests of the health service. The examinations in the surveillance programme are episodic, and economic considerations prevent most of them from being performed in the child's own environment. The results are therefore substantially biased. Additional difficulties are generated by approaching the surveillance as a form of medical diagnosis or test. Anxieties about the future health of the child or about their own guilt can be projected by the parents on to the "sick" or "failed" child to the detriment of the entire family. The dangers of seeking "abnormal" development have been mentioned with regard to health surveillance, and it would be more helpful to orientate the service toward health education and family counselling rather than merely towards the detection of some sort of clinical abnormality.

Nevertheless, development surveillance does offer the health service an excellent opportunity to stimulate the optimal development of the child within the context of full family participation. Within the framework of the "self-realization" model discussed earlier this could have substantial consequences for the child's readiness for schooling. Consideration should be given to the involvement of additional personnel, such as psychologists or educationists, in this process. Wherever possible, the parents should be encouraged to monitor the child's development themselves. Such parental participation in the surveillance programme, provided that it is in the context of helping the child to achieve his full potential rather than that of monitoring his achievements, may be much more effective in detecting abnormalities than professional surveillance alone. This is particularly likely, given that such

continuing observation is maintained by familiar people in the child's own familiar environment. Parents should be provided with the tools to undertake such a role and health education programmes should prepare them for this.

5. ADMINISTRATIVE ISSUES

5.1 Programme evaluation

Programmes should not only be evaluated before they are introduced, but they should also be capable of adjusting to new knowledge, improved techniques and to changes in disease patterns.

5.2 Psychological considerations

Since normal development relies heavily on adequate psychological adjustment and because many of the handicaps suffered by people in society are psychological in nature, no detection programme ought to be established without considering the psychological implications. Before a programme is established, psychologists have a fundamental role in training the people concerned in the programme, mainly with regard to their attitudes towards handicap, but more particularly in terms of counselling skills. If the handicapped child is to be integrated in society then it is even more important for psychological training in this field to be diversified, and the medical school undergraduate curriculum is the appropriate place for this.

In the planning process itself psychologists can be of immense help in identifying high-risk groups who, by virtue of their psychological reaction to their environment, enhance the general risk related to their social or physical state. The realization of the psychology of screening will encourage the development of procedures and processes with as few hazards as possible. Anxieties, projected fears, guilt, rejection and all the other abnormal though common compensation mechanisms discussed earlier could be foreseen by psychologists and appropriate counter-strategies identified. Those carrying out programme evaluation, particularly that involving research into innovations, should also include psychologists. This is to ensure the fullest consideration of psychological matters and to permit the observation of psychological phenomena which might not be apparent to the nonspecialist.

Psychological research and observation is of the utmost importance in this particular field. The important subject of bonding was first discovered by experimental psychologists in animal studies and later came to be applied to the human condition. This unfortunately took a considerable time and a certain amount of damage has been done in the interim period. It was once

thought that infants in the first few weeks after birth were capable of little more than experiencing hunger, pain and temperature and were able to respond merely by sleeping and crying. Psychologists' observations[a] have now revealed that, even in the first week, the neonatal nervous system is capable of many complex functions. Moreover, it is now recognized that even at 2 weeks the infant is capable of imitating certain simple acts such as protruding the tongue or opening the mouth.[a] Clearly, insights such as these will have a substantial influence on both the planning and the operation of early detection programmes which encompass normal development.

The detection of psychological problems as part of the standard programme is not quite so straightforward. In-depth interviewing by a professional psychologist is a very efficient way of determining the psychological status of any given individual, but it is clearly very expensive. To overcome this problem there has been much investment in simple questionnaires for psychological testing. There are a large number of tests now available which are as effective as psychological interviews, but they still need to be performed by trained psychologists. The performance of tests designed for use by nonpsychologists has been disappointing and there is a great need for further research in this field. The role of psychologists in assessing and evaluating problems detected by people working with children, or by their parents, is most important. In particular, there should be clear lines of referral for specialist psychological assessment of the child and/or his family in all confirmed or suspected cases of handicap. Consideration should also be given to the potential value of developing a psychological information and counselling service in the context of an integrated child health system. The latter is particularly important if secondary handicaps related to the family of the handicapped child are to be avoided. Regular assessment of the handicapped child and its family will be of great benefit in detecting secondary handicaps relating to family or community reaction to the child. Such surveillance could be a valuable tool in detecting family dysfunction and could ultimately have a major effect on the handicapped child.

Psychological considerations therefore feature prominently in secondary and tertiary preventive campaigns, and psychologists have an important role to play in the secondary care of the handicapped child and its family.

5.3 Sociological considerations

Sociological analysis can be a powerful tool in identifying social factors involved in the production of handicap, and pinpointing not only the etiological agents in primary or secondary handicap but also certain social concepts (such as stigma or deviance) that encourage the development of damaging

[a] **Maratos, O.** Personal communication

secondary handicaps. The consequences of defining people as being "at risk" can also be investigated by sociological means. The possibility of such research detecting an "at risk role" (see section 2.2) increases its value considerably. This poorly-understood state is likely to become increasingly important as data accumulate about its impact on social life.

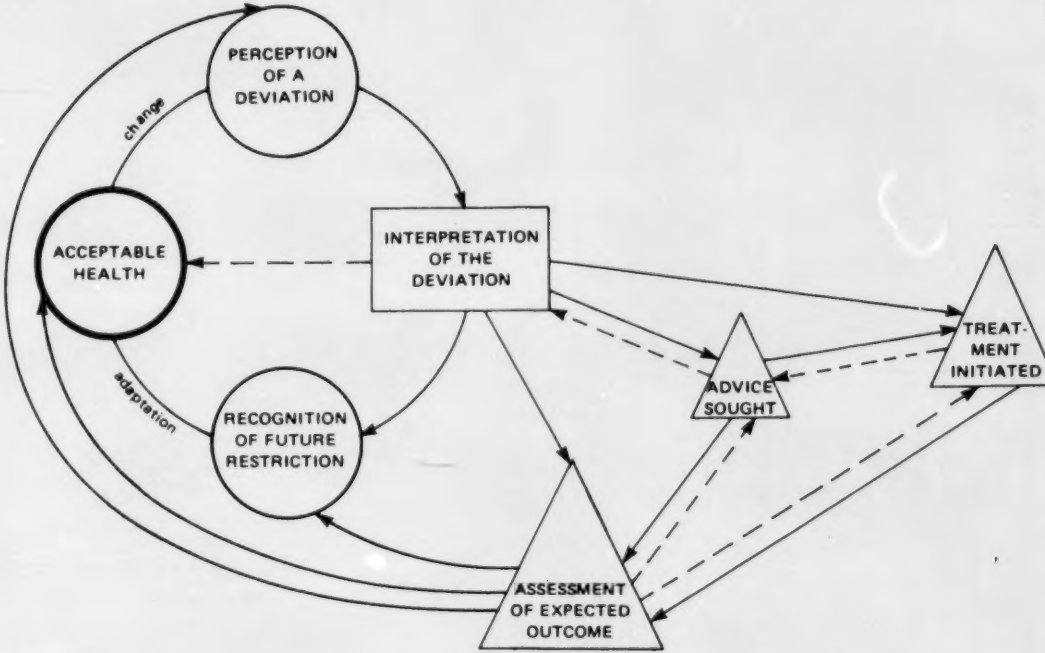
Sociological analysis can be of special use in providing some understanding of the problems of service uptake (*19*) and inequalities in resource distribution. In many countries it is still to a certain extent true that provision of services is inversely related to need (*20*); this appears to be linked to the motivation and attitudes of the professionals involved, and also to the environmental attractiveness and the workload of the areas served. Even where services are spread evenly, this may not have compensated for increased needs related to social factors such as isolation or malnutrition, especially where these have not hitherto been recognized as risks (see section 2.4).

Sociologists have shown that the quality of care varies according to factors such as socioeconomic status. One investigator found that the duration of antenatal care tends to be shortest "for women with four children and women bearing an illegitimate child", and that "heavy overrepresentation of these two groups among the lower classes accounts for their reduced duration of prenatal care" (*21, 22*). This sociological dissection of social behaviour at the lay-professional interface is fundamental to the proper understanding of apparent service inequity.

From here we can move directly to the uptake of services. It is often assumed that people who perceive an illness in themselves or who are informed that they have an illness will naturally behave as if they were ill. It is assumed that they will adopt some sort of "sick role" (*23*) through which they will be granted exemption from social roles in return for seeking professional help and complying with the prescribed treatment. This is now known to be an invalid generalization. The phenomenon of cognitive dissonance mentioned above (section 2.3) leads many people to reject perceived illness or to refuse to pay it any attention. Even if they do pay attention to the illness, there is no evidence that they will act according to professionally determined management plans. Illness-behaviour is much more complex than this and is best illustrated by Fig. 4.

From this model the process is seen to be flexible and convoluted, with the possibility of multiple backtracking. The key here is the notion of *acceptable health*. This is defined as "perceived well-being, whether or not disease or disability is present, provided that the latter does not interfere either with the sufferer's normal life or with that of people whom he or she may affect through community living" (*24*). This is, of course, not an operational definition but it is one which most people would have in mind when determining their subsequent behaviour. It has many similarities with the description of handicap outlined in section 2.1 above. Sociological analysis can help

Fig. 4. Decision processes in an illness



29 *Source:* **Williamson, J.D. & Danaher, K.** *Self-care in health.* London, Croom Helm, 1978.

to identify factors which lead people to perceive a particular state, acceptable or otherwise, and it can then help to explain the wide variety of manouevres adopted to resolve their problem. It is the difference between the perceptions and attitudes of professionals on the one hand and lay people on the other that explains to a considerable extent the poor uptake of detection programmes for handicap in children.

In the United Kingdom the uptake of surveillance programmes is far from universal. Approximately 80% attend for examination in the first year and fewer than 30% in the second and fourth year. One study (*11*) showed that 35% of children who did not attend for routine examinations were "at risk", compared with 22% who had attended. Similar shortfalls have been avoided in Sweden by increasing the accessibility of the special clinics, by the incorporation of home visits and by the involvement of parents both in the surveillance programme itself and in group discussions.[a] In Czechoslovakia, outreach into the families' homes is a major element of the programme[b] and other countries have adopted a variety of methods, including the linkage of social security benefits to registered clinic attendances (*11*). The determination of the appropriate policy for maximizing uptake therefore depends on the nature of society, its structure, its organization and its attitude towards self-determination by the patients concerned. The sociological method is uniquely appropriate for the study of all these areas.

5.4 Economic considerations

It is often claimed that detection programmes offer substantial economic benefits which should be taken into account when allocating resources. It is argued that the cost of providing detection programmes would be more than offset by the fact that finding preventable conditions early would save resources needed to look after the handicapped individual for the rest of his life. This view is mistaken, for a number of reasons:

(1) it ignores the costs borne by parents, by relatives and by many services for handicapped individuals provided by private and voluntary agencies;

(2) it ignores the costs borne by private individuals to take time off from work or to pay for transport to attend the screening programme;

(3) it does not take into account the fact that even a partially handicapped person whose disorder has been halted by early detection needs to withdraw from some activity, or that some of his relatives may be obliged to withdraw from the economic market to some extent.

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[a] Sundelin, C. Personal communication

[b] Stembera, Z. Personal communication

(4) it tends to assume that all costs incurred in caring for a handicapped person will be saved, even when this might not be the case, since some costs are applicable to normal individuals (e.g., food and clothing).

Economic comparisons of different policy options are by no means simple or clear-cut.

Another problem frequently overlooked is that while screening costs are incurred in the present, the benefits generally accrue later. The comparison of cost-benefit ratios cannot be effected by simple additions and subtractions. Apart from inflation, which needs to be considered, there is the more difficult problem of "discounting". Here it is necessary to consider not only the likely value of the money in the distant future but also the addition which might have been made from investing it in the most profitable way at the present. If the savings made by detection programmes over future expenditure on the caring services are to be "discounted" they become correspondingly less valuable economically.

The purpose of economic analysis, however, is not simply to decide what the costs and benefits of prespecified programmes are, but to help decide the form and extent of the programme itself. Economic considerations will help planners to decide who should be screened, what procedures are to be followed, and which screening activities should be combined in a given detection programme. Uptake of services is clearly an important area for economic analysis. At any given level of service provision there will be a certain proportion of the population at risk who will default. Without an economic perspective it is possible that the programme could be expanded to increase uptake, though when this has been done in other parts of the health service it has been shown that even a modest improvement in uptake requires a massive additional investment of funds (*25*). Economic analysis will show the financial benefits of a variety of programmes and these can then be considered by the planning team with regard both to their subjective value to society or to the patients concerned and to the opportunity costs (i.e., the money absorbed by the enlarged programme which cannot thereafter be used by other parts of the health service).

But economic decisions can only be made on the basis of adequate valid data. There is therefore considerable advantage in having an economist involved in the planning process of any major new programme to ensure that the information system established for the programme will permit the sort of economic analysis required for future planning decisions. For smaller programmes it is not necessary to have an economist directly involved but it might be useful for easy-to-comprehend advice on the incorporation of economic considerations to be made available to administrators and researchers.[a]

[a] **Glass, N.** Personal communication

5.5 Epidemiological considerations

All programmes should be monitored. Consideration should be given to the development of information systems for existing programmes and all new programmes should have built-in monitoring systems to permit programme evaluation. Regional variations can be identified especially quickly with careful monitoring and it is possible for fresh environmental assaults to be detected early. It is also possible for local monitoring to detect changes in treatment patterns, and this can be important in suggesting potential improvements in service provision.

One of the most important characteristics of monitoring is that the very process of collecting information serves to improve the efficiency of the service (*26*). It is as though the constant awareness of those aspects of the service being monitored stimulates staff to be particularly meticulous in respect of these. It is equally possible to monitor specific elements of the programme, such as certain aspects of the clinical examination (e.g., blood pressure), both to control the accuracy of the results and to act as a stimulus for staff retraining (*27*).

Monitoring of the service taken up by the individual child and its family is clearly an important task. Further consideration should be given to achieving this in the context of integrated health records which should include records held within the curative part of the health service. As far as possible the preventive and curative services should be integrated. All contacts with the patient and information collected from him/her should be noted in the integrated health record. It is possible that much of this information could be transmitted to epidemiologists for programme evaluation, but the problems of data protection should be considered very carefully.

In all these areas epidemiological techniques are of the utmost importance, but it is in the field of international monitoring or cross-national studies that they are shown to be indispensable. Such studies are all the more important as medicine comes to tackle those forms of handicap which are relatively rare in the childhood population of any one country. The difficulty with such cross-national observations is the main interest for epidemiology, the definition of the disorder and the population in which it is occurring.

In some countries registration of births starts from the 28th week, irrespective of whether the product of conception is live or dead. In other countries registration covers births occurring at earlier gestation periods. As a substantial proportion of deaths between the 20th and 34th weeks of gestation probably occur because of malformations, the inclusion of such "births" will inflate the incidence with reference to other countries. Some countries only register live-born children and others only those children who survive for a specified time; both categories of children will have a lower "incidence" of malformation. Some countries recognize this problem and compensate by various mathematical means, but this serves merely to make the comparison of national experiences even more difficult.

The true incidence of handicap can only be assessed by properly controlled epidemiological definition and data collection. This may call for more information than is currently collected. Malformed foetuses lost through spontaneous or legal abortion are an obvious problem. If these are to be included in the incidence statistics as they should be, some sort of policy regarding the examination of the removed products of conception by pathologists will have to be agreed. Some malformations are not evident at birth: only 10% of heart defects are detected at birth, while most are clear at 2 years; only 10% of endocrine disorders are recognized at birth, while nearly 80% are known at 3 years.[a] Properly determined incidence data provide the basis for most preventive and management programmes. Yet, because of all these complications in the field of handicap, these data may not be obtained unless there is continuing registration of the handicapped population in some sort of handicap register.

5.6 Handicap registers

Most countries have not established handicap registers because of the difficulties of avoiding "double counting" of notified patients. To do so requires that the handicapped person must be identified in the register, a policy to which many communities are opposed. However, the use of sophisticated codes by local notifying agencies for central processing might overcome such opposition and it would then be possible to develop local safeguards within the health service to prevent double counting.

A second major difficulty concerns the cases to be notified, i.e., which problems and which degrees of handicap should be included. Once again this is a function of our lack of clear definition in this field. This problem is especially significant when data from a wide variety of sources, which may view handicap in very different ways, are to be brought together in a single register.

One major handicap register was established over 20 years ago in British Columbia, Canada (*28*). To keep it updated, information is fed into it from a wide variety of sources, including (a) birth notification; (b) stillbirth notification; (c) obstetric discharge summaries; (d) death registration of children under 6 years; (e) child health service notifications; (f) hospital discharge summaries; (g) assessment centre notifications; (h) notifications from voluntary agencies for the handicapped; (i) notifications from general practitioners; (j) notifications from the Department of Human Resources on all disabled individuals who receive benefits. Clearly this list is by no means complete; many other sources could be involved in a holistic notification programme.

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[a] **Weatherall, J.A.C.** Personal communication.

The experience gained in maintaining the British Columbia register is that a proper understanding of the numbers and nature of the local handicapped population has been acquired. In the absence of such understanding elsewhere, the institution of a handicap register would appear to be quite appropriate. Further consideration of this subject might be particularly fruitful for future research.

6. PERSONNEL

6.1 Health care teams

In general terms, screening should be undertaken by the least trained person who is competent for the task. The essential rider to this is that where short-term goals (see section 3.4) are important it may be difficult to state succinctly what level of competence is actually required.

Nevertheless, since the service for the early detection of handicap is essentially child-oriented, with the aim of maximizing the child's achievement of its potential, it is clear that there has to be some element of cooperation between the various people involved with the child. This can best be achieved within a health care team, although this does not imply that everyone needs to work in the same place, or that it is necessary to meet as a team at regular intervals, or that there has to be an identifiable leader. On the other hand, there is nothing to prevent any of these features from being practised.

Where teams are developed at the primary care level, parents of "at-risk" or handicapped children need to relate to one person whom they can hold in trust. It would be beneficial for the family and the team alike if this person were to be seen as the pivot around which the work of the team revolved. He would be the focus for the collation of the various data collected by the team members.

In a comprehensive detection programme for handicap, doctors, midwives, nurses and a wide range of other professionals (including psychologists, dentists, opticians, audiometricians, speech therapists and physiotherapists) are involved. Most of these are involved directly, but because of the complex nature of handicap it could be argued that in the detection of handicap there is a place for every health worker coming into contact with a given child. Every contact with the patient should be considered in terms of its impact on future handicap.

The indirect approach can be seen in the field of family planning. If the doctor prescribing oral contraceptives is careful then he will take care to advise his patient how to set about conceiving, even if she has expressed no wish to do so. This is essential, for, if she should conceive within the first cycle

after ceasing to take the contraceptive, not only will the obstetrician be unsure of the foetus's gestation,[a] but there may be an increased risk of minor congenital malformation, particularly undescended testes (*29*).

Other indirect roles in the detection of handicap exist for the doctor when he is aware of family problems which increase the child's risk of primary or secondary handicap, or when he sees the child incidentally in the course of examining a parent or a sibling. In addition, many handicaps are first mentioned by a parent as an aside during the course of a consultation on a personal health problem. At very least, this is a means by which the problem of poor uptake of detection programmes can be attacked.

6.2 Multidisciplinary teams

If the detection of handicap is to be widened to include social disorders, clearly there has to be some involvement of social workers and juvenile officers attached to law courts. If language difficulties are to be included, then some educational input will be of use, and in those circumstances where readiness for school is a problem, input from preschool teachers and educationists will be particularly important. Surveillance by the staff of public day-care institutions could become a powerful tool in future detection programmes. An integrated preschool day-care and educational centre serving a defined population, especially when a strong element of social work can be incorporated, seems to be an even more attractive solution to the problems of caring for and educating young children, while at the same time yielding possibilities for detection programmes.[b] Such a centre could easily be attached to a child health centre. In any case, all detection programmes should be closely integrated into the child health service. The earlier suggestion (see section 5.2) that psychologists should be involved in the assessment of children or the counselling of families might be easier to realize in the context of such an institution.

Apart from these public day-care institutions, there are a variety of voluntary play groups which could be involved in surveillance if the playleaders and other caring personnel were trained in child development and in the detection of deviations from the normal. However, when personnel from outside the health service are involved in screening programmes it is crucial to identify them and communicate to them the referral pathways to be used.

A final issue is that, while such caring personnel may have no actual role in identifying or diagnosing a problem, their overall impression of the child might be of great value to the child health service. The exchange of useful

[a] **Williamson, J.D.** Personal communication

[b] **Kalverboer, L.** Personal communication

information between the health service and other social or educational services is a matter which should be considered in all early detection programmes.

6.3 Parental involvement

It is clearly advantageous for the parents to be involved as much as possible in the development of their child. Wherever possible they should be encouraged to participate in and monitor its progress. Sources of help available to parents of a child with a perceived problem should be clearly identified and free from all unnecessary barriers. Where possible, parents should be trained in surveillance methods so that their effectiveness in detecting abnormalities can be enhanced. On the other hand, parents should be discouraged from observing the child's development as though it were a series of hurdles to be sucessfully cleared as fast as possible. To this end, consideration should be given to providing facilities for parents to come together in discussion groups with professionals from various disciplines to discuss the positive aspects of child-rearing and child development as well as their problems.

In terms of tertiary prevention, parents' groups should be established for educational purposes by the assessment and management teams at handicap centres. In addition, parents should be encouraged to join together in mutual aid groups to offer each other support and to help identify the range of normal behaviour to be expected in a handicapped child. Parents can then be introduced to detection programmes through the medium of such groups and they can devise surveillance methods appropriate to the disabilities of their children. The feedback from such groups can be of tremendous value in the training of professional staff.

Two aspects of parental involvement seem to be particularly important. First, at all stages in the detection and management process parents should be fully informed of (a) the rationale behind detection, (b) the potential hazards of the investigation, (c) the interpretation of results, and (d) the possible therapeutic outcomes. Second, a problem which is recognized by the family should not be dismissed on the evidence of professional opinion; perception of a problem within the family is the only evidence necessary to initiate action, although the family's interpretation of that problem may not necessarily be the correct one.

6.4 Training

Everyone who comes into contact with children should be trained with a view to cooperating in the early detection of handicaps. Such training would include (a) the norms and values of society and the profession concerned with regard to handicap; (b) the normal processes of growth and development; (c) techniques for the early detection of handicap; (d) the

management of "at-risk" patients and families; (e) the management of handicapped children and their families; (f) the detection of secondary handicaps in handicapped children and their families; (g) the psychological, sociological and educational implications of handicap. Those working with handicapped children should also be taught the limitations of specified handicaps, certain relevant aspects of tertiary prevention, and the problems of monitoring the health of handicapped children.

Working with handicapped children should be regarded as a normal part of the basic training programme. This is especially important if the handicapped are to become fully integrated into normal society. Similarly, learning to share decision making with the parents of handicapped or potentially handicapped children is a crucial exercise for all staff working in early detection programmes. Only then can parents be fully involved in the programme.

One major aspect of training is the need to break down interprofessional barriers which may impair the management of the handicapped child and its family. Where such barriers exist and are structurally impossible to dismantle, there should be special programmes for training people how to circumvent these in the most efficient manner from the point of view of the handicapped child and its family.

Parents are best trained through the medium of parents' groups. A child health service should investigate the establishment of such groups to provide further health education for parents of both normal and handicapped children. Future health education programmes in schools should include child-rearing and child development as a normal part of their syllabus, and teachers should receive training in the teaching of these vital subjects.

7. RESEARCH

7.1 Small-scale research projects

The Working Group identified a large number of areas where additional research is needed. Some of this research can be conducted in the context of small-scale and isolated research projects. These include: (a) delineation of anomaly, defect and handicap syndromes for subsequent inclusion in the International Classification of Diseases; (b) the development of operational definitions of defect, disorder, disability and handicap; (c) the elucidation of the "at risk" concept in pregnancy and child development; (d) the evaluation of a number of tools used for detection (including psychological tests), with special reference to specificity, sensitivity and predictive power; their capacity for inducing secondary handicap, and their acceptability to the population concerned; (e) local programme evaluation; (f) comparative assessment of

various local methods of epidemiological monitoring; (g) research into the communication problems inherent in multidisciplinary work; and (h) research into the effectiveness of early training programmes for both professional and nonprofessional audiences.

7.2 Quantitative models

In the complete elucidation of the role of various sociological and psychological risk factors in the development of handicap there is a place for the relatively elaborate mathematical, computer simulation techniques in which the outputs are quantitative and representative of alternative levels of action. Such techniques would permit arbitrary or normative weightings of the various risk factors to be made. They would also allow the interaction of the risks to be monitored and quantified so as to enable a proper weighting to be identified for future simulations.

Such methods are common to operational research but have only recently been applied to the medical services, yet they have an obvious place there. "Experiments carried out in series, with resources set at successively high levels, provide outputs expressed in terms of cuts in morbidity and mortality, and also in marginal terms by declaring additional benefits and additional hazards created by each additional investment or alternative deployment of resources" (*12*).

7.3 Cross-national studies

In view of the social nature of many handicaps, the impact of social attitudes and expectations on the development of secondary handicaps, and the variable, if not random, manner in which health services have developed throughout the Region, there is considerable value in undertaking cross-national studies to clarify some of the etiological, nosological and operational problems in the field of handicap. For similar reasons, cross-national assessments of the different effects of particular risks in different societies will help to identify areas for future psychological and sociological research. Such studies might be undertaken as an important first step in developing research questions to be answered by the methods suggested in the two preceding paragraphs.

8. CONCLUSIONS

The Working Group recognized the difficulty of defining the major concepts of handicap and disability, and noted that the correlation between

detected defect and handicap is poor. Many handicaps are socially defined, either in terms of a notion of cultural normality or by virtue of the fact that the handicapped individual is unable to meet the demands made of him by the society in which he lives. The recognition of a handicap in an individual may in itself stimulate the development of secondary handicaps related to the way in which the handicapped person is adversely perceived by himself, by his family, or by the community as a whole. Because of this problem of definition, handicapped people may be underrated in terms of their normal functioning, with the result that any subsequent development of additional, though otherwise unrelated, handicap is either undetected or implicitly linked with the existing handicap and ignored.

The implications of these problems of definition for the detection process are substantial, since most screening programmes rely on the delineation of an "at-risk" group. The definition of such people is bound up with cultural values and is at present largely unsound.

While there is general agreement on the need for surveillance systems, there is tremendous disparity in the organization and methods adopted in various countries. For the most part, health services for children have developed irregularly in response to apparent need and the pressure of demand; very few surveillance systems were evaluated before they were introduced and still fewer had information systems built into them to permit adequate monitoring. This has resulted in a wide variety of nationally uniform procedures whose performances cannot be adequately compared.

There is some doubt as to the health impact of certain programmes, including developmental and behavioural screening. Furthermore, the psychological and sociological consequences of the various programmes seem to have been largely ignored. Finally, the need for a detection programme is linked to the presence and performance of coexisting primary preventive programmes, but there is little evidence that this notion has been used in the development of most detection programmes.

9. RECOMMENDATIONS

1. All pregnant women should be assessed to determine not only the risks to the mother but also the risk of handicap to the child. Those women deemed to be at high risk should receive a full explanation of that risk, of the investigations available to clarify any remaining uncertainty, and of the subsequent therapeutic possibilities. All high-risk pregnancies should be closely monitored and women in this category should be confined in a hospital where full supportive services are available.

2. Consideration should be given to the question of terminating pregnancies in which the foetus is confirmed to have significant handicap. Where termination is a possibility, this should be communicated to the mother to allow her to decide whether or not she wishes further investigation.

3. Every child should be examined in the first few days of life by staff specially trained in the examination of newborn infants. Every child should be given subsequent clinical examination and investigation to detect physical abnormalities such as phenylketonuria, hypothyroidism, deafness and visual impairment at the most appropriate time for effective management.

4. Every child should be monitored from the point of view of growth and general development. These monitoring processes should involve the parents as much as possible, even to the extent of delegating elements of surveillance to parents who are able and willing to undertake such a task.

5. Programmes should be restricted to detecting those conditions which are identifiable and for which appropriate management is available. In this context, management includes reassurance or support of the parents as appropriate. Programmes should be designed with a view to maximizing uptake of the services by the population at risk and finding the best balance between equity and efficiency. All programmes should include an element for detecting secondary handicaps that develop in children already diagnosed as handicapped, whether such additional handicaps are physical, psychological or social in origin.

6. Programmes should be as simple and flexible as possible. Any complexities related to detecting handicap at an early stage must be justified by the benefits of such timely intervention.

7. Before a programme is initiated it should be subjected to detailed scrutiny, in whole and in part, to ensure that it is acceptable, equitable, effective and efficient, and that its benefits, financial and otherwise, are deemed sufficient in relation to its cost. All programmes should be monitored continuously and any part failing to achieve its objectives should be corrected or abandoned.

8. Sociological, economic and epidemiological considerations are crucial to programme planning and evaluation. They should be introduced into the planning process at the earliest possible stage to ensure that appropriate monitoring systems can be developed, so as to permit continuous programme evaluation. In particular, easily comprehensible advice on the incorporation of economic considerations should be made available to all administrators and researchers.

9. Epidemiological monitoring is the prime tool of programme evaluation and can provide a sensitive means of detecting changes in the total incidence of handicap, but to avoid "double counting" such monitoring needs either to be limited to a single-point determination of handicap or (in order to include handicaps appearing at later stages) to include some element of record linkage. Consideration should therefore be given to data protection in collecting information from diverse sources. Consideration should also be given to problems of confidentiality when the detection process involves information-sharing between professional and nonprofessional groups.

10. Effective detection or monitoring programmes require the involvement of a wide variety of people working with children, including doctors, nurses, psychologists, nursery nurses, preschool teachers and child-minders. Such an integrated approach is best achieved through the development of multidisciplinary teams, both at planning and at service levels. In general terms, any screening programme should use the least skilled person competent to undertake the task, bearing in mind the psychological and sociological implications of the screening process. Where problems are detected, there should be clear referral pathways; these should be free of any unnecessary barriers which might delay the assessment of children.

11. All those involved in the detection of handicap should undergo training which includes forms of examination, family counselling, and the surveillance of handicapped children. They should be taught the psychological and sociological consequences of labelling people "at risk", as well as those of handicap and the diagnosis (or labelling) of handicap. Positive attitudes towards handicapped children and their families should be reinforced. Family members and others should be encouraged to adopt supportive rather than authoritarian roles.

12. Every person coming into contact with a child or its family should be aware of the developmental implications of the work and should be encouraged to use the contact to assist and cooperate in the prevention and detection of handicap.

13. It should be recognized that the handicapped child is a human being in his own right and that the degree of normal functioning usually far outweighs the degree of abnormal functioning. Wherever possible, the handicapped child should receive the same curative medical services as other children. To this end, the management and investigation of the handicapped child from the point of view of coexisting problems should be included in all relevant training programmes.

14. With such a wide variety of services and personnel available for the "at-risk" or handicapped child and its family, it is useful for the whole

family to relate to one central professional figure who is held in a position of trust. This person should be regarded as the central figure in any early detection programme and consideration should be given to the way in which he should receive and collate the various assessments on a particular child into a unified health record.

15. Parents should be involved as much as possible in the detection process and should be fully aware of the limitations and potentials of their handicapped child as soon as this is apparent to the assessment team. Consideration should be given to developing centres within the integrated child health service where parents can receive information and/or advice on general psychological issues (including emotional and behavioural problems) arising in the process of child-rearing and in which psychologists have a fundamental role to play. Before such a service is introduced, there should be some attempt at assessing its potential outcome and establishing process or performance criteria.

16. Parents' mutual aid groups should be encouraged to help service providers and the caring professions in the detection process and tertiary prevention to cope with the social and psychological effects of handicap in the family context, and to encourage the development of a more positive attitude towards handicap on the part of society at large.

17. Since certain handicaps are rare, because some are social or environmental in origin, and because of the variation between countries in the incidence of handicap and the health services' response to it, there is considerable value in cross-national studies in the field of handicap. These studies will help to determine the relative importance of various possible etiological factors, the definition of the handicap and its incidence, the effect of the handicap on the child and its family, the secondary handicapping aspects of the initial handicap, and the impact of the various services already provided in response to this problem in different countries.

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Annex

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